

# Mental Health In Autosomal Dominant Polycystic Kidney Disease (ADPKD)

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## ADPKD Can Affect Quality Of Life (QoL)\* & Psychosocial Well-Being†1,2

## Psychological Impact Of ADPKD<sup>3</sup>

Patients with ADPKD have high rates of depression and anxiety.

### QUALITY OF LIFE (QOL) IMPACT & DISEASE PROGRESSION

Even early in ADPKD, patients report being less happy with their lives compared to healthy individuals.<sup>2</sup> Anxiety and depression affect many of these patients.<sup>1</sup>



1

### RELATIONSHIP TO MORTALITY RATES

Experiencing anxiety and depression during early ADPKD stages predicts higher death rates in later disease stages.<sup>1</sup>



2

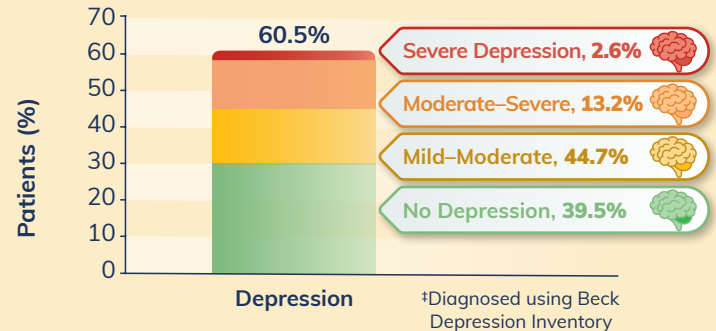
### MANAGEMENT

Finding and treating patients' anxiety and depression in early stages can improve QoL. This is as important as medical treatment.<sup>1</sup>

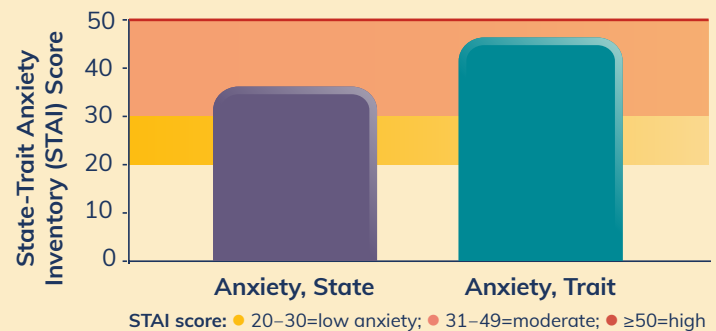


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### Patients With ADPKD (n=38)†



### Anxiety In Patients With ADPKD<sup>3</sup>



## Psychosocial Risks Of ADPKD<sup>4</sup>

### Risk Factors For Adverse Psychosocial Well-Being

Female Gender

Increasing Age

Impaired Renal Function

Loss Of First Degree Relative To ADPKD

Increasing Kidney Size

22%

22% of study participants reported significant depression.

62%

62% reported feeling guilty about passing ADPKD to their children.

## Burden Of ADPKD On QoL<sup>5</sup>



\*Quality of life: An individual's well-being and ability to function in life activities. It includes emotional, social, and physical aspects.

†Psychosocial: A combination of social, mental, and physical influences on an individual's well-being.

#### References:

1. Yarioglu AM, et al. *Int Urol Nephrol*. 2023;55(4):983-992.
2. Jankowska M, et al. *Nephron*. 2024;148(4):224-229.
3. de Barros BP, et al. *J Bras Nefrol*. 2011;33(2):120-128.

4. Simms RJ, et al. *Nephrol Dial Transplant*. 2016;31(7):1130-1140.

5. Barhum L. Living with autosomal dominant polycystic kidney disease: coping, support, and living well. Updated June 19, 2024. Accessed July 17, 2024. <https://www.verywellhealth.com/autosomal-dominant-polycystic-kidney-disease-coping-5211944>

6. Baker A, et al. *Clin Kidney J*. 2015;8(5):531-537.

7. Harris T, et al. *Nephrol Dial Transplant*. 2018;33(4):563-573.

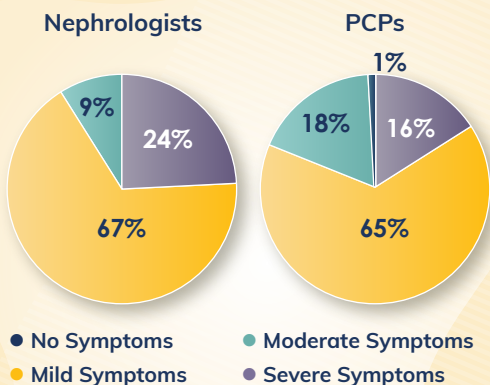
8. Kim DS, et al. *Korean J Intern Med*. 2022;37(3):489-501.

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## Impact Of ADPKD On Patients May Be Underestimated By Healthcare Providers<sup>6</sup>

HCPs may not recognize the severity of physical symptoms experienced during early-stage ADPKD.



### European Survey:

- Approximately two-thirds of nephrologists and primary care physicians believed that patients with early-stage ADPKD had only **mild symptoms**.
- A quarter of nephrologists believed that these patients had **no symptoms at all**.
- Approximately half of both groups (52%) believed that early-stage ADPKD was **not associated with any emotional symptoms**, or was associated with only mild symptoms.

## Healthcare Specialties That Can Provide Care To Patients With ADPKD<sup>7</sup>

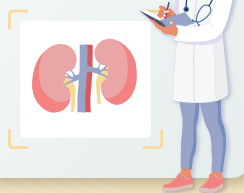
### Diagnosis & Assessment

#### Genetics

- General testing and counseling

#### Radiology

- Detailed imaging (renal and non-renal)
- Total kidney volume estimation
- Intracerebral aneurysm



### Specialist Care

#### Adult Or Pediatric Nephrology

- Initial assessment
- Follow-up care
- End-stage renal disease management
- Total kidney volume/prognostic assessment
- Complications
- Renoprotective drug therapy
- Research (trials, registries, etc)

#### ADPKD Specialty Care

- Potential roles in disease and complications management and research coordination

### General & Follow-Up Care

#### Primary Care

- Follow-up, shared care

#### Renal Dietician

- Dietary education (salt and protein restriction)

#### Psychiatry/Psychology

- Psychosocial effects (eg, anxiety, depression)

#### Social Services

- Impact on daily life, finances, family, etc

### Manifestations & Complications

#### Cardiology

- Cardiac complications

#### Hepatology

- Hepatic cyst infection/bleeding
- Severe liver complications

#### Surgery

- Kidney, liver transplantation
- Aneurysms

#### Urology

- Urinary tract obstruction

#### Pain Management

- Chronic pain
- Physiotherapy

#### Ob/Gyn

- Prenatal counseling
- Maternal/fetal complications

## Early Identification & Screening<sup>3,4,7,8</sup>

### Self-Assessments

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- Patient Health Questionnaire-9 (PHQ-9), Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI)<sup>3,4,8</sup>
- Genetic Psychosocial Risk Instrument for ADPKD (GPRI-ADPKD)<sup>4</sup>
- ADPKD Impact Scale (ADPKD-IS)<sup>7</sup>

### Clinical Interview

2



## Resources For Patients, Families, & Caregivers To Enable Informed & Active Participation In Care\*

### Access To Psychological & Social Support Services<sup>7</sup>

### Support Call Lines

PKD Hope Line:  
844-PKD-HOPE

### Peer Mentoring

PKDConnect:  
[connect.pkdcure.org](http://connect.pkdcure.org)

### Renal Replacement Therapy & Transplant<sup>7</sup>

Explore options for living kidney donors early on for preemptive kidney transplant

### Patient/Caregiver Ed.

OPEN:  
[otsukapatented.com](http://otsukapatented.com)  
PKD Foundation:  
[resources.pkdcure.org](http://resources.pkdcure.org)  
NKF: [kidney.org](http://kidney.org)

### Family Planning<sup>7</sup>

- Genetic counseling
- Pre-implantation genetic diagnosis
- Contraception
- Pregnancy issues

### Informative Sites

PKD Foundation:  
[pkdcure.org](http://pkdcure.org)  
PKD International:  
[pkdinternational.org](http://pkdinternational.org)

### Referral To Centers Of Excellence & Partner Clinics

PKD Foundation:  
[pkdcure.org](http://pkdcure.org)

### Research Participation<sup>7</sup>

Registry entry, clinical trials, and patient-reported outcome data collection

\*Not an exhaustive list.

#### References:

1. Yarioglu AM, et al. *Int Urol Nephrol*. 2023;55(4):983-992.
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